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Understanding patterns and factors associated with place of death in patients with end-stage kidney disease: A retrospective cohort study

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Abstract

Background: Meeting place-of-death preferences is an important measure of the quality of end-of-life care. Systematic review shows that 42% of end-stage kidney disease patients prefer home death. Little research has been undertaken on place of death.

Aim: To understand patterns of place of death in patients with end-stage kidney disease known in one UK renal unit.

Design: A retrospective cohort study of all patients with chronic kidney disease stage 4–5, age ⩾75 and known to one UK renal unit, who died between 2006 and 2012. Patients were categorised into three management pathways: haemodialysis, conservative and pre-dialysis.

Results: A total of 321 patients (mean age, 82.7; standard deviation, 5.21) died (61.7% male). In all, 62.9% died in hospital (95% confidence interval, 57.5%–68.1%), 21.8% died in their usual place of residence (95% confidence interval, 17.5%–26.6%) and 15.3% died in an inpatient palliative care unit (95% confidence interval, 11.6%–19.5%). Management pathway and living circumstances were most strongly associated with place of death. Patients on the conservative pathway had four times the odds of dying out of hospital (odds ratio, 4.0; 95% confidence interval, 2.1–7.5; $p < 0.01$). Patients living alone were less likely to die out of hospital (odds ratio, 0.3; 95% confidence interval, 0.1–0.6; $p < 0.01$). There were also changes in place of death over time, with more patients dying out of hospital in 2012 compared to 2006 (odds ratio, 3.1; 95% confidence interval, 1.0–9.7; $p < 0.05$).

Conclusion: Most patients with end-stage kidney disease die in hospital, but patients managed without dialysis are significantly more likely to die outside of hospital. Planning ahead is key to be able to meet preference for place of death.

Keywords

End-stage renal failure, chronic kidney diseases, palliative care, attitude to death, patient preference

What is already known about the topic?

- Meeting preferences for place of death is an important measure of the quality of end-of-life care provided.
- Preference for home death in end-stage kidney disease is estimated at 42%.
- Hospital remains the most common place of death (58% between 2001 and 2008).

What this paper adds?

- Key factors may influence place of death in renal disease, in particular renal management pathway, living circumstances and development of palliative care services within renal units.

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Implications for practice, theory or policy

- Planning ahead is key to be able to meet preference for place of death.
- This is particularly important for patients receiving dialysis and those living alone.

Introduction

Meeting preferences for place of death is an important measure of the quality of end-of-life care provided. A survey conducted in the United Kingdom found that two-thirds of the public would prefer to die at home.[1,2] Systematic review of 210 studies reported preferences for over 100,000 people from 33 countries. Preferences for dying at home ranged from 31% to 87% for patients, 25% to 64% for caregivers and 49% to 70% for the public.[3] Preference for home death in non-malignant conditions varies in comparison. Just under half of people with advanced non-malignant conditions reported a preference for home death[4] and in end-stage kidney disease has been estimated at 42%.[4]

Data suggest recent increases in the number of home and hospice deaths in line with these preferences; however, hospital remains the most common place of death.[5,6] These changing trends may reflect implementation of the National End-of-life Care Programme in the United Kingdom. In England and Wales, home deaths have increased from 18.3% to 20.8% (between 2004 and 2010), although the rise was more pronounced in cancer compared to non-cancer.[7] There is marked incongruence between preferred and actual place of death, most pronounced in non-cancer diagnoses.[8]

Several factors have been shown to be associated with place of death.[5] Marital status is the second most important factor, after type of cancer; married people were more likely to achieve a home death than those who were single, divorced or widowed.[5] Furthermore, a systematic literature review for patients with non-malignant conditions identifies that the presence of a family or informal carer is a key component in achieving a home death.[4]

The number of people with non-malignant conditions accessing specialist palliative care services is increasing, and within hospital and outpatient services now accounts for at least 20% of all diagnoses.[9] In specialist palliative care inpatient units, the proportion of patients with a non-malignant diagnosis has increased from 3% in 1998 to 11% in 2011.[9]

Aim

To understand patterns of place of death in patients with end-stage kidney disease known to one UK renal team.

Design

Study design was a single-centre retrospective cohort study. Patients with chronic kidney disease stage 4–5, age 75 and above, and known to 1 UK renal team, who died over a 7-year period (2006–2012) were included. End-stage kidney disease is recognised as a disease of older people and therefore due to small numbers, patients under the age of 75 were excluded from analysis. Patients were identified by the renal team and included the following three management pathways: haemodialysis (currently receiving dialysis), conservative (treatment without dialysis) and pre-dialysis (estimated glomerular filtration rate < 20 but not receiving dialysis). The pre-dialysis management pathway includes patients who do not yet require renal replacement therapy and have not chosen the conservative care pathway. These patients are being actively educated and prepared for dialysis. The conservative management pathway was categorised using existing guidelines (International Society of Nephrology). Management excludes dialysis but does include interventions to delay progression of disease, shared decision making, active symptom management, advance care planning, psychological support, social and family support, and cultural and spiritual domains of care.[10]

Patients receiving peritoneal dialysis were excluded due to small numbers. Demographic and clinical variables were collected including management pathway and living circumstances, variables known to be associated with place of death.[4,5,11] Living circumstances were divided into the following categories: living with a family member, living alone, living in a care home or living circumstances not documented. Data were not available for preference of place of death. Place of death was categorised as hospital, usual place of residence or inpatient palliative care unit. Multi-variable regression analysis was undertaken to determine the relationship with place of death. Following guidance from the local Research and Design Department (King's College Hospital Foundation Trust), this work was registered as a service evaluation project with the Clinical Effectiveness Team (CASS number 2892). This article follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement checklist.[12]

Results

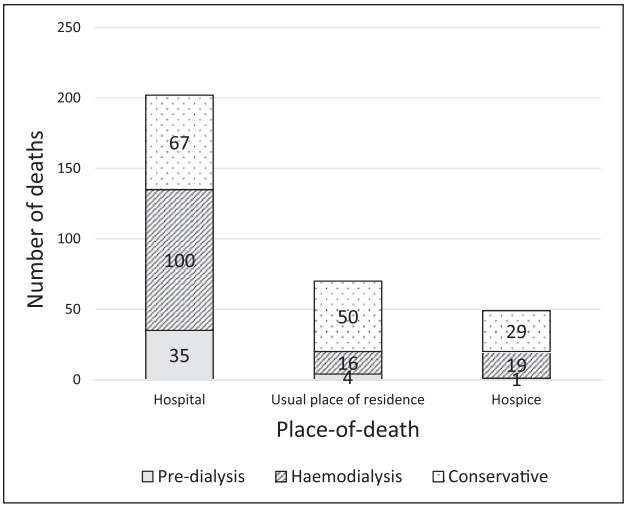
A total of 321 patients were included. Patient characteristics are shown in Table 1. Mean age was 82.7 (standard deviation (SD), 5.21). In total, 61.7% were male; 62.9% died in hospital (95% confidence interval (CI), 57.5%–68.1%), 21.8% died in their usual place of residence (95% CI, 17.5%–26.6%) and 15.3% died in an inpatient palliative care unit (95% CI, 11.6%–19.5%). A total of 202

Table 1. Patient characteristics.

Patient characteristics	*N*	%
Number	321	
Sex		
Male	198	61.7
Female	123	38.3
Place of death		
Hospital	202	62.9
Usual residence	70	21.8
Inpatient palliative care unit	49	15.3
Year of death		
2006	31	9.7
2007	32	10.0
2008	32	10.0
2009	48	14.9
2010	48	14.9
2011	63	19.6
2012	67	20.9
Marital status		
Married	139	43.3
Widowed	39	12.1
Not documented	124	38.6
Single	14	4.4
Divorced	5	1.6
Age (years)		
75–79	106	33
80–84	106	33
85–89	73	22.7
90–94	28	8.7
95–99	8	2.5
Living arrangement		
With family/friend	144	44.9
Alone	89	27.7
Not documented	56	17.4
Care home	32	10
Management pathway		
Haemodialysis	135	42.1
Pre-dialysis	40	12.5
Conservative	146	45.5

patients died in hospital: 35 pre-dialysis, 100 haemodialysis and 67 conservative management pathway. In all, 70 patients died in their usual place of residence: 4 pre-dialysis, 16 haemodialysis and 50 conservative management pathway. A total of 49 patients died in a hospice: 1 pre-dialysis, 19 haemodialysis and 29 conservative management pathway. These data are also presented in Graph 1.

In all, 42.1% of deaths were in the haemodialysis management group (95% CI, 36.7%–47.5%), 45.5% in the conservative management group (95% CI, 40.1%–60.0%) and 12.5% in the pre-dialysis management group (95% CI, 8.9%–16.1%). Management pathway and residential setting were most strongly associated with place of death. There were also changes in place of death over time. Patients in the conservative (non-dialytic) pathway had



Graph 1. Place of death based on management pathway.

four times the odds of dying out of hospital (odds ratio (OR), 4.0; 95% CI, 2.1–7.5; $p < 0.01$) (Table 2). Patients living alone were less likely to die out of hospital (OR, 0.3; 95% CI, 0.1–0.6; $p < 0.01$) (Table 2). Those where living status was not documented were less likely to die out of hospital (OR, 0.4; 95% CI, 0.2–1.0; $p < 0.05$) (Table 2). Patients living in a care home had 5.2 times the odds of dying out of hospital (OR, 5.2; 95% CI, 1.8–15.0; $p < 0.01$) (Table 2). Patients dying in 2012 had 3.1 times the odds of dying out of hospital when compared to patients dying in 2006 (OR, 3.1; 95% CI, 1.0–9.7; $p < 0.05$) (Table 2). The increase in out-of-hospital deaths is predominantly seen in the conservative management group although a trend is noticeable in all management pathways (Table 3, Graph 2).

Discussion

Despite preference for a home death, this study confirms that most patients with end-stage kidney disease die in hospital. This study shows that place of death varied by management pathway, consistent with national data, and out-of-hospital deaths are highest in the group of patients managed conservatively. In this unit, patients managed conservatively are reviewed in a dedicated clinic, and consultations maintain focus on symptoms and preferences for place of care and death. In comparison, patients receiving haemodialysis spend nearly 50% of their time in a health setting. Furthermore, it is the experience of this unit that both patients in the pre-dialysis and haemodialysis groups are at a higher risk of sudden death. All of these factors need further exploration in future studies.

Although not statistically significant, these data suggest that older people are more likely to die in hospital. This could be the result of an ageing population, increasing frailty and the presence of multi-morbidity. Absence of a care giver at home may be a factor. Furthermore, this study identified that patients living in a care home had five times

Table 2. Odds ratios: age, management pathway, marital status, who patient lived with and year of death.

	B	*p* value	Odds ratio	95% CI for odds ratio	
				Lower	Upper
Gender (female)	0.355	0.222	1.427	0.807	2.522
Age					
75–79 (reference)		0.966			
80–84	−0.2	0.571	0.819	0.41	1.635
85–89	−0.233	0.56	0.792	0.362	1.735
90–94	−0.35	0.529	0.705	0.237	2.096
95–99	−0.208	0.817	0.813	0.141	4.699
Mode					
Haemodialysis (reference)		0			
Pre-dialysis	−0.647	0.243	0.524	0.177	1.553
Conservative	1.391	0	4.017	2.147	7.517
Marital status					
Married (reference)		0.767			
Widowed	0.466	0.324	1.594	0.631	4.022
Not known	0.225	0.535	1.252	0.616	2.546
Single	0.669	0.325	1.951	0.516	7.385
Divorced	0.827	0.438	2.286	0.283	18.479
Who patient lived with					
Family (reference)		0			
Alone	−1.268	0.002	0.281	0.127	0.623
Not documented	−0.83	0.049	0.436	0.191	0.997
Care home	1.655	0.002	5.235	1.831	14.969
Year of death					
2006 (reference)		0.209			
2007	0.074	0.913	1.077	0.287	4.039
2008	0.69	0.294	1.995	0.55	7.233
2009	0.905	0.136	2.472	0.751	8.134
2010	1.116	0.065	3.053	0.934	9.976
2011	1.209	0.036	3.35	1.084	10.35
2012	1.141	0.048	3.131	1.01	9.708
Constant	−1.986	0.001	0.137		

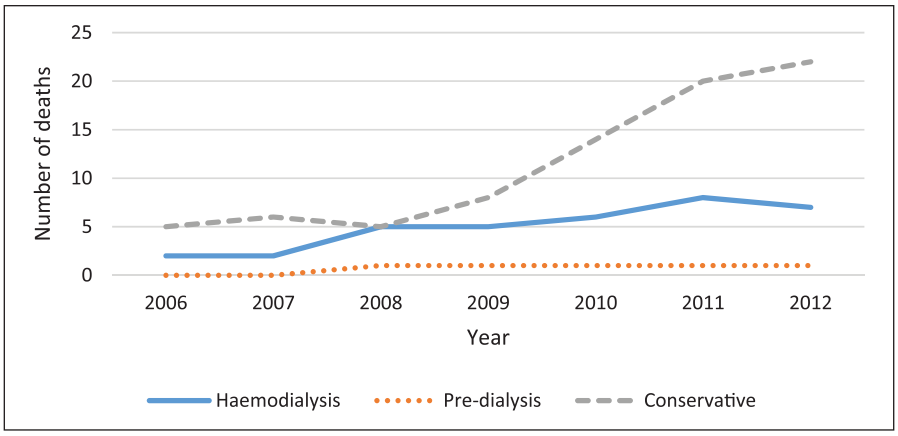
CI: confidence interval.

Table 3. Out-of-hospital deaths over time based on management pathway.

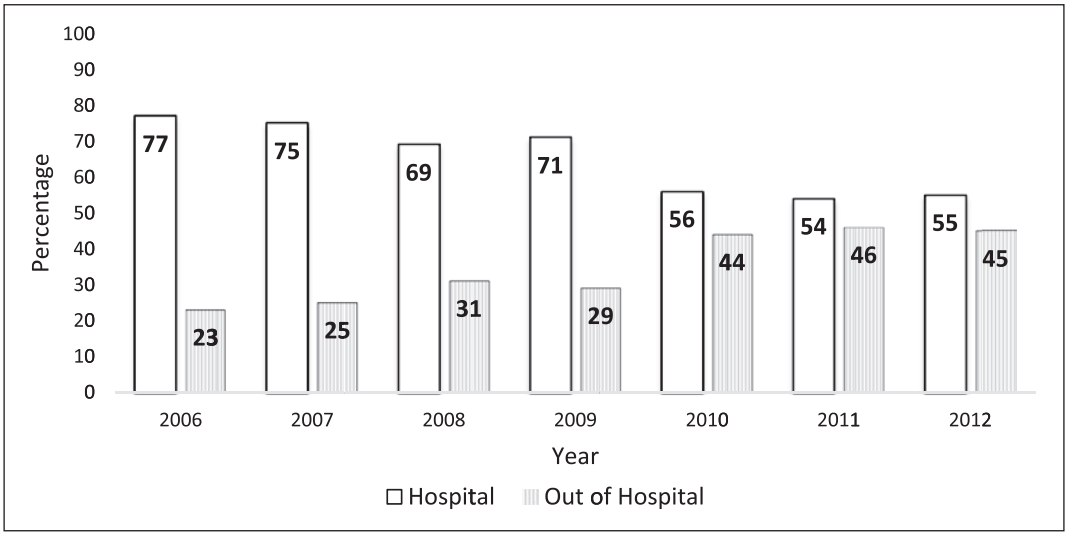
	Year						
	2006	2007	2008	2009	2010	2011	2012
Management pathway							
Haemodialysis	2	2	5	5	6	8	7
Pre-dialysis	0	0	1	1	1	1	1
Conservative	5	6	5	8	14	20	22

the odds of dying out of hospital. It may be that this cohort of patients has more detailed care plans, but the full reasons for this need further research.

This study identifies factors associated with place of death in this population including management pathway and place of residence. This supports previous work and highlights the importance of considering management pathway and living circumstances, so we are able to better meet preferences for place of death in this population.[11,13] This study also demonstrates a change over time, with more patients dying out of hospital in 2012 when compared to 2006 (Graph 3). This may represent the impact of palliative care service development within this renal unit for conservatively managed patients (through the Advanced Renal Care Project)[14] and is important to consider when planning services in the future.



Graph 2. Out-of-hospital deaths over time based on management pathway.



Graph 3. Proportion of out-of-hospital deaths over time.

This study was limited to the data available and we were therefore unable to analyse and compare patients' preferred place of death with their actual place of death. Preferences regarding place of death have been highlighted as an important aspect of advance care planning and future work could incorporate this. We were also unable to specifically investigate the effect of cause of death on place of death. It is possible that cause of death may explain some of the difference in place of death in the different management groups. These are important considerations when collecting data in the future, so that we can better meet preference for place of death in this population.

Conclusion

This article identifies key factors, which may influence place of death in renal disease, in particular renal management pathway, living circumstances and development of palliative care services. For patients receiving dialysis and those living alone, planning ahead is key to be able to meet preference for place of death.

Declaration of conflicting interests

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